Arizona Department of Health Services Office for Children with Special Health Care Needs Integrated Services Grant

Statewide Task Force Meeting Summary August 23, 2006

Purpose: The Task Force will facilitate the development of partnerships between agencies and communities to evaluate the service delivery system for CYSHCN and make recommendations on more effective community-based systems.

Meeting Objective:

Review status and recommendations from each of the Committees, and as needed make decisions regarding the recommendations.

Participants

Joan Agostinelli, Adrienne Akers (phone), Tanis Bryan, Karla Birkholz, Linda Cannon, Mike Clement, Diana Denboba (phone), Patti Hackett (phone), Ida Fitch for Barbara Brent, Tom Kirsch (phone), Bill Rosenfeld (phone), Katharine Levandowsky, Gifford Loda, Sharman Ober-Reynolds for Raun Melmed, Rafael Figueroa for Joyce Millard-Hoie, Laura Nelson, Richard Porter, Sheila Sjolander, Jason Geroux for Jami Snyder, Bonnie Strickland (phone), Carol Takao, Roy Teramoto, Ashleigh Turner (phone), Jill Wendt, Linda Hamman, Becky Hamblin

MEETING ITEM	SPEAKER	DISCUSSION	ACTION ITEMS
Welcome and	Joan	Joan welcomed the participants and led introductions.	
Introductions	Agostinelli		
		Joan announced the appointment of Jill Wendt as the Integrated Services Grant Project Director.	
ISG Grant Status & Next Steps	Linda Cannon	Linda Cannon provided background information on what the grant has done and what Year 2 holds. The Year 2 grant has been approved.	Schedule a meeting with Molly Dries
		Linda Cannon asked participants if they felt as though they have the information needed to participate as Task Force members. No concerns were expressed.	
		In terms of Next Steps, Jill Wendt indicated that the Task Force will be asked to approve a revised approach to the Care Coordination Study at today's meeting. Jill also reported updates on the activities	

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		of each Committee will be provided today and we will discuss later in the agenda the idea of forming an Executive Committee of the Task Force that could provide guidance on issues raised between Task Force meetings.	
		Adrienne Akers stated that previously they had arranged with Molly Dries to do investigations into the options for a shared data system. Adrienne asked if this is something we are still doing and what is the status. Linda Cannon responded that this opportunity is on the action list for the Task Force and will continue to be explored.	
Task Force Priorities	Jill Wendt	Medical Home Project	
		 Care Coordination Study Jill Wendt reviewed the purpose and proposed approach to the Care Coordination Study with the Task Force. The purpose of the study is to provide well-documented coordination strategies that link medical homes to other community-based services and other health-related needs. Determine the effectiveness of use of the screening tools and of the strategies for conducting screening Determine youth and parent knowledge level and needs regarding transition issues Based on the care coordination effort, determine 1) children, youth and family satisfaction with care coordination; 2) gaps in service, 3) effective community-based linkages used by the care coordinator Determine medical provider satisfaction with screening and care coordination The proposed Approach includes the following components: The OSCHCN Medical Home Program Manager will have lead responsibility for implementation of the Care Coordination 	Go forward with the revised approach to the Care Coordination Study

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		Study. 2. A professional evaluator will be hired to define, implement and analyze the information and produce the study report. 3. Community Development Teams will be an integral part of the implementation of the study through the following roles: • Assist in identifying local physician practices that are willing and able to participate in the study • Assist in identifying / hiring of the Screener and Care Coordinator positions at each of the three study sites • Work directly with the Care Coordinator in their geographic area to identify community-based services needed and create the linkages to these services • Provide outreach services to engage children, youth and families to participate in the study • Assist in the review of findings and development of recommendations 4. Screener & Care Coordinator positions: Each site will have a Screener and a Care Coordinator. Job descriptions for these positions will be based on the National Medical Home standards. • Screening will be provided for all children / youth presenting at a study site • The following tools have been selected for conducting the screening: • Children with Special Health Care Needs Screen (CSHCN) • Parents' Evaluation of Developmental Status (PEDS) • Modified Checklist for Autism (M-CHAT) • Pediatric Symptom Checklist (PSC) • CRAFFT • Dental Screen from the Association of State and Territorial Dental Directors • GAPS * Upon Task Force Approval 8/23/06 5. The Integrated Services Task Force will review the proposed	

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		plan, monitor results each quarter and provide recommendations for modification of the plan. Ultimately, the Task Force will develop and approve recommendations based on the result of the Study, to be presented to the Governor.	
		Jill asked for discussion and approval of the proposed approach. By Consensus agreement, the Task Force approved going forward with this plan.	
		Jill indicated that the Medical Home Program position is close to being filled. The person hired will be the primary lead for the Study. The position has been upgraded to a higher level that increases the talents needed to qualify.	
		Jill also announced that B. J. Tatro will be joining the Team to help define the evaluation components of the Care Coordination Study. The Community Action Team members have not yet been approached on their role in the Study, but now that approval has	
		been received to go forward; they will be contacted in September. They are crucial to its success. In May, Oly Cowles and Linda Hammann presented on the CDI to this Task Force. The Community Action Teams that OCSHCN supports are statewide. They can offer a lot of resources. Their involvement will further	
		define what we would like them to do with the study. The Community Action Teams are the most knowledgeable about their communities. They can also help with hiring the Care Coordinator and Screener. They would then work with the Care Coordinator. We are looking at having three medical home sites. We will not be	
		doing school-based sites in the study. Adrienne Akers stated that it would open the door into rural communities. Pocatello, Idaho has a community screening process	
		that she will send for review. There are different models out there that do not require new staff. If you wish to discuss this further,	

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		please contact Jill. Decision: The Task Force voted to go forward with the proposed approach to the Care Coordination Study. List serv status Jill reported that the list serv implementation and e-learning scheduled for implementation in July is now in the testing phase. This tool will be especially good for engaging more young adults in	
Committee Updates & Recommendations	Jill Wendt	Task Force/Committee activities. Linda Hamman and Oly Cowles gave a presentation to the Governor's Council. The report is on the web site at www.azis.gov. If anyone has trouble accessing the report please let Jill know. Jill reported that the committees are functioning well. There is great talent on the committees. If you participate in one of the Committees and see how Linda Cannon and Jill can help with the committees, let us know. If you are new to the grant and would like to review the meeting minutes or the agendas, they can be viewed on the web site at www.isg.gov.	New member to review meeting minutes or agendas on the web site www.isg.gov
Screening Tools Update	Jill Wendt	Screening Tools Update The Quality Improvement Clinical Team is looking for a chairperson. Jill will be acting as the temporary facilitator. The Adolescent Health Group recommended the GAPS as the additional screening tool. Adolescent Health, Young Adult Transition, Parent Action Council and QI Clinical discussed the tool and would like the Task Force to include GAPS as an approved screening tool in the Medical Home Project / Care Coordination Study. In response to a question about how we integrate the screening information into the physician's office, Jill indicated that that protocol will be part of the study. We have been working on this for years. Having families use this in the medical home site is wonderful and gives us a chance to work the process in the	 Designate a Chairperson for Quality Improvement Clinical Team Will tool enhance services?

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		Physician's office. How do we address the confidentiality of the parent-youth? The screening tool is part of the medical record. Confidentiality is very important to young adults. Additional questions regarding the study included: Would it be an appropriate use of the Physician's time to do this? Do Physicians administer it now? If someone takes the time to do it, will it enhance the services and make an impact? What barriers are attached to it? Jill described the possible screening process as follows: All of the screening takes place prior to the patient seeing the Physician. It gives the Physician a more complete picture. A person comes in, completes the chart and scores it. If it is a positive result it is on the "right side" of the form. If an issue is identified we will be able to see it on the form very clearly. We looked at scored tools and found that more detailed scoring wasn't popular. Decision: Consensus that GAPS would be used for the Care Coordination Study.	
Cultural Competency Committee	Jill Wendt	 Cultural Competency Committee The objectives of the Cultural Competency Committee is to: Support participation of traditionally under-represented families in decision-making, educational and technical assistance activities. Develop Parent-Youth Leadership training materials that are culturally and linguistically appropriate for racially / ethnically diverse populations with special health care needs. Recruit additional members for the Community Development Teams that are representative of the economic, racial and ethnic diversity of the communities they serve. The Committee has looked at a couple objectives they wanted to	 Determine what tasks are doable and in line with the grant goals Recruit additional members to the Community Action Teams. Develop incentives for participation Include faith-

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		work on. Part of the challenge is honing in on what is doable and in	based
		line with the grant goals.	organizations
Adolescent Health Community Advisory Group	Karla Birkholz	We are developing and will implement a community questionnaire. We are waiting for feedback from various committees on the questionnaire. It will bring people from the communities to the table. The key question is how can we move forward in a culturally competent way? We want to ensure the appropriate parties review everything that is developed. We need to recruit additional members to the Community Action Teams. We can utilize grant dollars to facilitate participation by family members and possibly develop incentives for participation. The faith-based organizations must be included. The Hopi Team is up and running and doing wonderful things. The Sickle Cell Parent Action Team is working hard. These are both new teams. Diana Denboba raised the issue of cultural competence versus cultural appropriateness. There is a difference between the two and how you report and define them. The may be an opportunity to work with the National Center for Cultural Competence. Adolescent Health Community Advisory Group The Committee has held regular meetings. The Committee has reviewed the screening tools and how to use them as well as determining how to identify resources to implement the tools. Screening raises issues for Physicians. They are not always prepared to address the issue raised in the screening such as where to refer adolescents. We found that providing someone with a book isn't sufficient. We are trying to coordinate the resources that we have. There is not a lack of materials or a lack of talent. There is a need for one place to go for information that is easily accessed. The Committee is looking for a secondary grant to fund resources for someone to work full time on the web site.	Identify fund sources and opportunities for a grant writer

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		The overall goal is for clinicians to ask adolescents about their risk behaviors. We need to ensure that clinicians are educated on the best practices on caring for an adolescent and informing adolescents that they will be asked about their risk behaviors when they are seen by a clinician. There are two obstacles – consent and confidentiality. There is a lack of insurance for adolescent health care. The system is not comfortable with adolescent care and is not designed for it. The Committee has a lot of ideas of where to go for the money but	
Quality Improvement – Committee	Richard Porter	needs the support of a grant writer. Quality Improvement – Data Committee Richard Porter, Chair of the Data Committee, provided the following update: Objective 1.7 of the grant is: "To work with other agencies to share data systems." This objective can range from electronic medical records to data warehouses. We pulled together the data from DES, ADJC, Arizona Health Query and ADHS. We talked about the data they have and how to bring it together to be of value to this group. It was determined that an electronic health record is way too ambitious for the committee. At a subsequent meeting, each individual presented their data elements, what could be matched and the availability of that data to other places. The net result is that there are state and federal laws that restrict us from sharing information across systems. We cannot create a mechanism to share the data. We found ourselves at an impasse. We cannot bringing large data sets together and create a data warehouse because of these restrictions in law. There may be an opportunity to come up with aggregate (non- identifying) data if there is some value in doing that. The Committee would need to know what aggregate data would be useful. The group is disbanded until we are able to determine a solution to the data sharing issue.	 Is there specific information needed? Need to see what programs want and what would be of value, Adrienne Akers to keep the Task Force updated on newborn hearing screening when information is gathered.

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		Regarding Medical records, AHCCCS is moving forward on	
		electronic records. That would be a huge help for this committee.	
		They want to develop an electronic medical record within 2-3 years.	
		<u>Discussion</u> :	
		Regarding newborn hearing screening – Adrienne Akers indicated	
		that the inability to share information has also been raised in the	
		newborn screening program. She indicated that once we hear	
		anything about how this is working for newborn hearing screening,	
		Adrienne will let us know.	
		Aggregating information would be useful. We need to know any	
		child that is receiving state program services. Is the identifiable	
		information a barrier? If we identify an aggregate data source, we	
		can get the data. We need to look at the impact of using a screening	
		tool. Can we look at the data that can be shared that AzHealthQuery	
		can provide? We need to look at which set of children are getting	
		which services from which agencies and what can be shared.	
		We could collect medical data from different sources and try to	
		merge and match to individuals. From that, we could respond to	
		health issues. Data from hospitals, vital records, immunization,	
		discharge information, from OCSHCN and Community Health	
		Centers are collected but it is incomplete data.	
		HealthQuery does not own its data, it is owned by the individuals.	
		Molly Dries is involved with a universal application task force. No	
		matter what door a person comes in, you can make referrals to other	
		agencies. One of the questions was: "Would you mind if I shared	
		the information?" Would that override HIPAA and FERPA	
		requirements?	
		It would be interesting to look historically at the services the children	
		or young adults are accessing through the system. How many drop	
		off AHCCCS at transition? How do you know if someone	
		drops off? If someone drops off, how do you know why?	

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		This data would not be helpful for evaluating the value of the grant. It will help us look at trends and also help us ask better questions. Right now we don't know what it will bring. St. Joseph's Hospital tapped into Health Query for a community needs assessment. The data they have is interesting. They found a lot of young Hispanic adults giving birth and their addresses are located around St. Joseph's. It would be useful for this grant and maybe we can identify duplication of services. If we don't know it's happening, we can't identify it. We need to formulate questions first. We can agree that we won't use personally identifying information. Does Telemed data go into Health Query? The purpose of the committee is to look at quality data. Find out what data can be used. Keep us informed as you look into Health Query.	
	Jill Wendt	Other Updates Young Adult Transition The purpose is to prepare youth, families, pediatric and adult health care providers and the educational system for transition. A Youth Summit is planned for 2007. They are working on transition issues for the Summit. The AZ DOE Transition Leadership Team is having a conference on youth in September. This is an opportunity for integration. We are looking for a link to Behavioral Health. BHS will help plan the Summit. The e-learning is a good opportunity because young adults don't have a lot of time. We need to identify additional youth. There have been discussions about using incarcerated youth to help plan issues and other adolescent issues. Any ideas on how to get incarcerated youth to the table would be appreciated. Let committee members know other avenues that may be tried. Also, resources or funding that may be available for the summit. We could create a funding resources committee.	 Increase BHS involvement Identify additional youth Pursue involvement of incarcerated youth with ADJC Identify additional resources or funding for the summit' Look into creation of a funding resources committee

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Education Training Committee		Education Training Committee This Committee has been formed and will begin meeting in September or October - Judi Walker will facilitate the Committee and Joyce Millard Hoie will chair the Committee	
Insurance Committee		Insurance Committee Wendy Benz will chair the committee. The Committee is just being formed so if you have ideas for membership, please contact Jill Wendt.	
		Youth Council Sheila Sjolander suggested that we make sure we are not duplicating the efforts of existing youth councils but are integrating them into our work. Sheila will work with Jill Wendt to identify the integration opportunities. Sheila said that people from the substance abuse coordination grant should be contacted. They have been doing statewide forums and reaching out to youth. As a result of that, they are connecting with youth that are interested in being active in this. BHS is administering the grant so they would be a good contact. Arizona Department of Education also has a youth council and so do local middle schools and high schools. Contact Steve Mishlove at DES for more information.	Contact persons on the Substance Abuse Coordination grant
	Linda Cannon	Executive Committee: It is crucial to understand what is going on with all the committees. The committees will bring their needs to the Task Force. There has been an internal conversation about having an executive committee that the committee and facilitators can go to for direction. We would like to identify three people from different areas such as government, health care and advocacy who could assist with problems. The anticipated immediate need will be with regard to the Care Coordination Study.	 Identify three persons to act as Executive Committee to assist committees List of participants and link to the web site provided to members

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		This work could be done with a conference call once a month if needed. Wendy Benz has volunteered for advocacy. Giff Loda also volunteered. Participants requested a list of all committees and which ones are working. Laura Nelson to discuss with Jill Wendt on how BHS can help with the committees. Dr. Birkholz would like a list of participants and the link to the web site.	
Announcements	Task Force Members	 Laura Nelson announced that Norma Garcia Torres with BHS, Interagency Bureau is working with sister agencies to increase collaboration and communication. We continue to have monthly Children's Executive Committee meetings. Raising Special Kids is kicking off its work at a third hospital on September 6th. There are a lot of referrals on "premmies". Sharman Ober-Reynolds - SARRC is recruiting for 2 positions - Adult Services and Director of Clinical Services Tanis Bryan - SWI is working with Jenny Rogers at the Navajo Nation. Community family parent group. Gifford Loda reported that St. Joseph's has picked up the University of Southern California lung transplant program and has applied for approval of the program to Medicare. This has great implications for the community to be able to get services locally for lung transplants. Katharine Levandowsky – A full match for Vocational Rehabilitation was received from the Legislature this year so there is no longer an order of selection in place. Katherine reported that RSA is strengthening its transition program with schools. Ida Fitch reported she is coordinating two programs at DES – One is an Early Childhood Task Force operates within DES. We are working to better integrate DES services. There are monthly newsletters sent out to include issues such as: What does it mean when school starts? Or why is childcare important? It is 	

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		 raising consciousness within in the department. Becky Hamblin – CDI update. We have a steering team. September-15 we will be working on our strategic plan. The Team encourages collaboration between the agencies and others to break down the barriers. A parent-leader training is scheduled in September on how to run teams and how to better organize their teams for action. We are looking at scheduling a follow up summit in 2007 on how communities implemented their strategies to create teams. The Conference won't happen until late spring or early summer. Most of what we have done is by invitation. We will do a statewide conference to show what we have done with communities and how to implement something. We have been asked to go to Washington D.C. about the CDI at an MCHB Conference. Bonnie Strickland – Congratulations on the Title V MCHB block grant. 	
Next Steps & Next Meeting		Next Steps Committees continue to work toward their objectives Implementation of the Care Coordination Study Implementation of the List Serv	
		Next Meeting November 15, 2006 – 1:00 – 3:00 pm – Room 345A	